

108TH CONGRESS  
1ST SESSION

# S. 1629

To improve the palliative and end-of-life care provided to children with life-threatening conditions, and for other purposes.

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## IN THE SENATE OF THE UNITED STATES

SEPTEMBER 17, 2003

Mr. DEWINE (for himself and Mr. DODD) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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## A BILL

To improve the palliative and end-of-life care provided to children with life-threatening conditions, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

### 3 **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as the  
5 “Children’s Compassionate Care Act of 2003”.

6 (b) TABLE OF CONTENTS.—The table of contents of  
7 this Act is as follows:

Sec. 1. Short title; table of contents.

TITLE I—GRANTS TO EXPAND PEDIATRIC PALLIATIVE CARE  
SERVICES AND RESEARCH

Sec. 101. Education and training.  
 Sec. 102. Grants to expand pediatric palliative care.  
 Sec. 103. Health professions fellowships and residency grants.  
 Sec. 104. Model program grants.  
 Sec. 105. Research.

## TITLE II—PEDIATRIC PALLIATIVE CARE DEMONSTRATION PROJECTS

Sec. 201. Medicare pediatric palliative care demonstration projects.  
 Sec. 202. Private sector pediatric palliative care demonstration projects.  
 Sec. 203. Authorization of appropriations.

# 1 **TITLE I—GRANTS TO EXPAND** 2 **PEDIATRIC PALLIATIVE CARE** 3 **SERVICES AND RESEARCH**

## 4 **SEC. 101. EDUCATION AND TRAINING.**

5 Subpart 2 of part E of title VII of the Public Health  
 6 Service Act (42 U.S.C. 295 et seq.) is amended—

7 (1) in section 770(a) by inserting “except for  
 8 section 771,” after “carrying out this subpart”; and  
 9 (2) by adding at the end the following:

## 10 **“SEC. 771. PEDIATRIC PALLIATIVE CARE SERVICES EDU-** 11 **CATION AND TRAINING.**

12 “(a) ESTABLISHMENT.—The Secretary may award  
 13 grants to eligible entities to provide training in pediatric  
 14 palliative care and related services.

15 “(b) ELIGIBLE ENTITY DEFINED.—

16 “(1) IN GENERAL.—In this section the term ‘el-  
 17 igible entity’ means a health care provider that is af-  
 18 filiated with an academic institution, that is pro-  
 19 viding comprehensive pediatric palliative care serv-  
 20 ices, alone or through an arrangement with another

1 entity, and that has demonstrated experience in pro-  
2 viding training and consultative services in pediatric  
3 palliative care including—

4 “(A) children’s hospitals or other hospitals  
5 or medical centers with significant capacity in  
6 caring for children with life-threatening condi-  
7 tions;

8 “(B) pediatric hospices or hospices with  
9 significant pediatric palliative care programs;

10 “(C) home health agencies with a dem-  
11 onstrated capacity to serve children with life-  
12 threatening conditions and that provide pedi-  
13 atric palliative care; and

14 “(D) any other entity that the Secretary  
15 determines is appropriate.

16 “(2) LIFE-THREATENING CONDITION DE-  
17 FINED.—In this subsection, the term ‘life-threat-  
18 ening condition’ has the meaning given such term by  
19 the Secretary (in consultation with hospice programs  
20 (as defined in section 1861(dd)(2) of the Social Se-  
21 curity Act (42 U.S.C. 1395x(dd)(2))) and academic  
22 experts in end-of-life care), except that the Secretary  
23 may not limit such term to individuals who are ter-  
24 minally ill (as defined in section 1861(dd)(3) of the  
25 Social Security Act (42 U.S.C. 1395x(dd)(3))).

1       “(c) AUTHORIZED ACTIVITIES.—Grant funds award-  
2 ed under subsection (a) shall be used to—

3               “(1) provide short-term training and education  
4 programs in pediatric palliative care for the range of  
5 interdisciplinary health professionals and others pro-  
6 viding such care;

7               “(2) provide consultative services and guidance  
8 to health care providers that are developing and  
9 building comprehensive pediatric palliative care pro-  
10 grams;

11              “(3) develop regional information outreach and  
12 other resources to assist clinicians and families in  
13 local and outlying communities and rural areas;

14              “(4) develop or evaluate current curricula and  
15 educational materials being used in providing such  
16 education and guidance relating to pediatric pallia-  
17 tive care;

18              “(5) facilitate the development, assessment, and  
19 implementation of clinical practice guidelines and in-  
20 stitutional protocols and procedures for pediatric  
21 palliative, end-of-life, and bereavement care; and

22              “(6) assure that families of children with life-  
23 threatening conditions are an integral part of these  
24 processes.

1 “(d) AUTHORIZATION OF APPROPRIATIONS.—There  
 2 are authorized to be appropriated to carry out this section  
 3 \$5,000,000 for each of fiscal years 2004 through 2008.”.

4 **SEC. 102. GRANTS TO EXPAND PEDIATRIC PALLIATIVE**  
 5 **CARE.**

6 Part Q of title III of the Public Health Service Act  
 7 (42 U.S.C. 280h et seq.) is amended by adding at the end  
 8 the following:

9 **“SEC. 399Z–1. GRANTS TO EXPAND PEDIATRIC PALLIATIVE**  
 10 **CARE.**

11 “(a) ESTABLISHMENT.—The Secretary, acting  
 12 through the Administrator of the Health Resources and  
 13 Services Administration, may award grants to eligible en-  
 14 tities to implement or expand pediatric palliative care pro-  
 15 grams for children with life-threatening conditions.

16 “(b) ELIGIBLE ENTITY DEFINED.—In this section,  
 17 the term ‘eligible entity’ means—

18 “(1) children’s hospitals or other hospitals with  
 19 a capacity and ability to care for children with life-  
 20 threatening conditions;

21 “(2) hospices with a demonstrated capacity and  
 22 ability to care for children with life-threatening con-  
 23 ditions and their families; and

24 “(3) home health agencies with—

1                   “(A) a demonstrated capacity and ability  
2                   to care for children with life-threatening condi-  
3                   tions; and

4                   “(B) expertise in providing palliative care.

5           “(c) AUTHORIZED ACTIVITIES.—Grant funds award-  
6 ed under subsection (a) shall be used to—

7                   “(1) create new pediatric palliative care pro-  
8                   grams;

9                   “(2) start or expand needed additional care set-  
10                  tings, such as respite, hospice, inpatient day serv-  
11                  ices, or other care settings to provide a continuum  
12                  of care across inpatient, home, and community-based  
13                  settings;

14                  “(3) expand comprehensive pediatric palliative  
15                  care services, including care coordination services, to  
16                  greater numbers of children and broader service  
17                  areas, including regional and rural outreach; and

18                  “(4) support communication linkages and care  
19                  coordination, telemedicine and teleconferencing, and  
20                  measures to improve patient safety.

21           “(d) APPLICATION.—Each eligible entity desiring a  
22 grant under this section shall submit an application to the  
23 Administrator at such time, in such manner, and con-  
24 taining such information as the Administrator may re-  
25 quire.

1 “(e) AUTHORIZATION OF APPROPRIATIONS.—There  
 2 are authorized to be appropriated to carry out this section  
 3 \$10,000,000 for each of fiscal years 2004 through 2008.”.

4 **SEC. 103. PEDIATRIC PALLIATIVE CARE TRAINING AND**  
 5 **RESIDENCY GRANTS.**

6 Part A of title IV of the Public Health Service Act  
 7 (42 U.S.C. 281 et seq.) is amended by adding at the end  
 8 the following:

9 **“SEC. 404F. PEDIATRIC PALLIATIVE CARE TRAINING AND**  
 10 **RESIDENCY GRANTS.**

11 “(a) ESTABLISHMENT.—The Director of the Na-  
 12 tional Institutes of Health is authorized to award training  
 13 grants to eligible entities to expand the number of physi-  
 14 cians, nurses, mental health professionals, and appropriate  
 15 allied health professionals and specialists (as determined  
 16 by the Secretary) with pediatric palliative clinical training  
 17 and research experience.

18 “(b) ELIGIBLE ENTITY DEFINED.—In this section,  
 19 the term ‘eligible entity’ means—

20 “(1) a pediatric department of a medical school  
 21 and other related departments including—

22 “(A) oncology;

23 “(B) virology;

24 “(C) neurology; and

25 “(D) psychiatry;

1           “(2) a school of nursing;

2           “(3) a school of psychology and social work;

3           and

4           “(4) a children’s hospital or other hospital with  
5           a significant number of pediatric patients with life-  
6           threatening conditions.

7           “(c) APPLICATION.—Each eligible entity desiring a  
8           grant under this section shall submit an application to the  
9           Director at such time, in such manner, and containing  
10          such information as the Director may require.

11          “(d) AUTHORIZATION OF APPROPRIATIONS.—There  
12          are authorized to be appropriated to carry out this section  
13          \$5,000,000 for each of fiscal years 2004 through 2008.”.

14       **SEC. 104. MODEL PROGRAM GRANTS.**

15          Part Q of title III of the Public Health Service Act  
16          (42 U.S.C. 280h et seq.), as amended by section 102, is  
17          further amended by adding at the end the following:

18       **“SEC. 399Z-2. MODEL PROGRAM GRANTS.**

19          “(a) ESTABLISHMENT.—The Secretary may award  
20          grants to eligible entities to enhance pediatric palliative  
21          care and care for children with life-threatening conditions  
22          in general pediatric or family practice residency training  
23          programs through the development of model programs.



1       “(b) ELIGIBLE ENTITY DEFINED.—In this section  
 2 the term ‘eligible entity’ means a pediatric department  
 3 of—

4               “(1) a medical school;

5               “(2) a children’s hospital; or

6               “(3) any other hospital with a general pediatric  
 7 or family practice residency program that serves a  
 8 significant number of pediatric patients with life-  
 9 threatening conditions.

10       “(c) APPLICATION.—Each eligible entity desiring a  
 11 grant under this section shall submit an application to the  
 12 Administrator at such time, in such manner, and con-  
 13 taining such information as the Administrator may re-  
 14 quire.

15       “(d) AUTHORIZATION OF APPROPRIATIONS.—There  
 16 are authorized to be appropriated to carry out this section  
 17 \$5,000,000 for each of fiscal years 2004 through 2008.”.

18 **SEC. 105. RESEARCH.**

19       (a) PAIN AND SYMPTOM MANAGEMENT.—The Direc-  
 20 tor of the National Institutes of Health (in this section  
 21 referred to as the “Director”) shall provide translational  
 22 research grants to fund research in pediatric pain and  
 23 symptom management that will utilize existing facilities  
 24 of the National Institutes of Health including—

25               (1) pediatric pharmacological research units;

1 (2) the general clinical research centers; and  
 2 (3) other centers providing infrastructure for  
 3 patient oriented research.

4 (b) ELIGIBLE ENTITIES.—In carrying out subsection  
 5 (a), the Director may award grants for the conduct of re-  
 6 search to—

- 7 (1) children’s hospitals or other hospitals serv-  
 8 ing a significant number of children with life-threat-  
 9 ening conditions;
- 10 (2) pediatric departments of medical schools;
- 11 (3) institutions currently participating in Na-  
 12 tional Institutes of Health network of pediatric  
 13 pharmacological research units; and
- 14 (4) hospices with pediatric palliative care pro-  
 15 grams and academic affiliations.

16 (c) AUTHORIZATION OF APPROPRIATIONS.—There  
 17 are authorized to be appropriated to carry out this section  
 18 \$10,000,000, to remain available until expended.

## 19 **TITLE II—PEDIATRIC PALLIA-** 20 **TIVE CARE DEMONSTRATION** 21 **PROJECTS**

### 22 **SEC. 201. MEDICARE PEDIATRIC PALLIATIVE CARE DEM-** 23 **ONSTRATION PROJECTS.**

24 (a) DEFINITIONS.—In this section:

1           (1) CARE COORDINATION SERVICES.—The term  
2           “care coordination services” means services that pro-  
3           vide for the coordination of, and assistance with, re-  
4           ferral for medical and other services, including mul-  
5           tidisciplinary care conferences, coordination with  
6           other providers involved in care of the eligible child,  
7           patient and family caregiver education and coun-  
8           seling, and such other services as the Secretary de-  
9           termines to be appropriate in order to facilitate the  
10          coordination and continuity of care furnished to an  
11          individual.

12          (2) DEMONSTRATION PROJECT.—The term  
13          “demonstration project” means a demonstration  
14          project established by the Secretary under sub-  
15          section (b)(1).

16          (3) ELIGIBLE CHILD.—The term “eligible  
17          child” means an individual with a life-threatening  
18          condition who is entitled to benefits under part A of  
19          the medicare program and who is under 18 years of  
20          age.

21          (4) ELIGIBLE PROVIDER.—The term “eligible  
22          provider” means—

23                (A) a pediatric palliative care program that  
24                is a public agency or private organization (or a  
25                subdivision thereof) which—

1 (i)(I) is primarily engaged in pro-  
2 viding the care and services described in  
3 section 1861(dd)(1) of the Social Security  
4 Act (42 U.S.C. 1395(dd)(1)) and makes  
5 such services available (as needed) on a  
6 24-hour basis and which also provides  
7 counseling (including bereavement coun-  
8 seling) for the immediate family of eligible  
9 children;

10 (II) provides for such care and serv-  
11 ices in eligible children's homes, on an out-  
12 patient basis, and on a short-term inpa-  
13 tient basis, directly or under arrangements  
14 made by the agency or organization, except  
15 that—

16 (aa) the agency or organization  
17 must routinely provide directly sub-  
18 stantially all of each of the services  
19 described in subparagraphs (A), (C),  
20 and (H) of such section 1861(dd)(1);

21 (bb) in the case of other services  
22 described in such section 1861(dd)(1)  
23 which are not provided directly by the  
24 agency or organization, the agency or  
25 organization must maintain profes-

- 1                   sional management responsibility for  
2                   all such services furnished to an eligi-  
3                   ble child, regardless of the location or  
4                   facility in which such services are fur-  
5                   nished; and
- 6                   (III)(aa) identifies medical, commu-  
7                   nity, and social service needs;
- 8                   (bb) simplifies access to service;
- 9                   (cc) uses the full range of community  
10                  resources, including the friends and family  
11                  of the eligible child; and
- 12                  (dd) provides educational opportuni-  
13                  ties relating to health care; and
- 14                  (ii) has an interdisciplinary group of  
15                  personnel which—
- 16                   (I) includes at least—
- 17                   (aa) 1 physician (as defined  
18                   in section 1861(r)(1) of the So-  
19                   cial Security Act (42 U.S.C.  
20                   1395x(r)(1)));
- 21                   (bb) 1 registered profes-  
22                   sional nurse; and
- 23                   (cc) 1 social worker;
- 24                  employed by or, in the case of a physi-  
25                  cian described in item (aa), under

1 contract with the agency or organiza-  
2 tion, and also includes at least 1 pas-  
3 toral or other counselor;

4 (II) provides (or supervises the provi-  
5 sion of) the care and services described in  
6 such section 1861(dd)(1); and

7 (III) establishes the policies governing  
8 the provision of such care and services;

9 (iii) maintains central clinical records  
10 on all patients;

11 (iv) does not discontinue the palliative  
12 care it provides with respect to an eligible  
13 child because of the inability of the eligible  
14 child to pay for such care;

15 (v)(I) uses volunteers in its provision  
16 of care and services in accordance with  
17 standards set by the Secretary, which  
18 standards shall ensure a continuing level of  
19 effort to use such volunteers; and

20 (II) maintains records on the use of  
21 these volunteers and the cost savings and  
22 expansion of care and services achieved  
23 through the use of these volunteers;

24 (vi) in the case of an agency or orga-  
25 nization in any State in which State or ap-

1 plicable local law provides for the licensing  
2 of agencies or organizations of this nature,  
3 is licensed pursuant to such law;

4 (vii) seeks to ensure that children and  
5 families receive complete, timely, under-  
6 standable information about diagnosis,  
7 prognosis, treatments, and palliative care  
8 options;

9 (viii) ensures that children and fami-  
10 lies participate in effective and timely pre-  
11 vention, assessment, and treatment of  
12 physical and psychological symptoms of  
13 distress; and

14 (ix) meets such other requirements as  
15 the Secretary may find necessary in the in-  
16 terest of the health and safety of the eligi-  
17 ble children who are provided with pallia-  
18 tive care by such agency or organization;  
19 and

20 (B) any other individual or entity with an  
21 agreement under section 1866 of the Social Se-  
22 curity Act (42 U.S.C. 1395cc) that—

23 (i) has demonstrated experience in  
24 providing interdisciplinary team-based pal-  
25 liative care and care coordination services

1 (as defined in paragraph (1)) to pediatric  
2 populations; and

3 (ii) the Secretary determines is appro-  
4 priate.

5 (5) LIFE-THREATENING CONDITION.—The term  
6 “life-threatening condition” has the meaning given  
7 such term by the Secretary (in consultation with  
8 hospice programs (as defined in section 1861(dd)(2)  
9 of the Social Security Act (42 U.S.C. 1395x(dd)(2)))  
10 and academic experts in end-of-life care), except that  
11 the Secretary may not limit such term to individuals  
12 who are terminally ill (as defined in section  
13 1861(dd)(3) of the Social Security Act (42 U.S.C.  
14 1395x(dd)(3))).

15 (6) MEDICARE PROGRAM.—The term “medicare  
16 program” means the health benefits program under  
17 title XVIII of the Social Security Act (42 U.S.C.  
18 1395 et seq.).

19 (7) SECRETARY.—The term “Secretary” means  
20 the Secretary of Health and Human Services.

21 (b) PEDIATRIC PALLIATIVE CARE DEMONSTRATION  
22 PROJECTS.—

23 (1) ESTABLISHMENT.—The Secretary shall es-  
24 tablish demonstration projects in accordance with



1 the provisions of this subsection to provide pediatric  
 2 palliative care to eligible children.

3 (2) PARTICIPATION.—

4 (A) ELIGIBLE PROVIDERS.—Any eligible  
 5 provider may furnish items or services covered  
 6 under the pediatric palliative care benefit.

7 (B) ELIGIBLE CHILDREN.—The Secretary  
 8 shall permit any eligible child residing in the  
 9 service area of an eligible provider participating  
 10 in a demonstration project to participate in  
 11 such project on a voluntary basis.

12 (c) SERVICES UNDER DEMONSTRATION  
 13 PROJECTS.—

14 (1) IN GENERAL.—Except as otherwise pro-  
 15 vided in this subsection, the provisions of section  
 16 1814(i) of the Social Security Act (42 U.S.C.  
 17 1395f(i)) shall apply to the payment for pediatric  
 18 palliative care provided under the demonstration  
 19 projects in the same manner in which such section  
 20 applies to the payment for hospice care (as defined  
 21 in section 1861(dd)(1) of the Social Security Act (42  
 22 U.S.C. 1395x(dd)(1))) provided under the medicare  
 23 program.

24 (2) COVERAGE OF PEDIATRIC PALLIATIVE  
 25 CARE.—

1 (A) IN GENERAL.—Notwithstanding sec-  
2 tion 1862(a)(1)(C) of the Social Security Act  
3 (42 U.S.C. 1395y(a)(1)(C)), the Secretary shall  
4 provide for reimbursement for items and serv-  
5 ices provided under the pediatric palliative care  
6 benefit made available under the demonstration  
7 projects in a manner that is consistent with the  
8 requirements of subparagraph (B).

9 (B) BENEFIT.—Under the pediatric pallia-  
10 tive care benefit, the following requirements  
11 shall apply:

12 (i) WAIVER OF REQUIREMENT TO  
13 ELECT HOSPICE CARE.—Each eligible child  
14 may receive benefits without an election  
15 under section 1812(d)(1) of the Social Se-  
16 curity Act (42 U.S.C. 1395d(d)(1)) to re-  
17 ceive hospice care (as defined in section  
18 1861(dd)(1) of such Act (42 U.S.C.  
19 1395x(dd)(1))) having been made with re-  
20 spect to the eligible child.

21 (ii) AUTHORIZATION FOR CURATIVE  
22 TREATMENT.—Each eligible child may con-  
23 tinue to receive benefits for disease and  
24 symptom modifying treatment under the  
25 medicare program.

1 (iii) PROVISION OF CARE COORDINA-  
 2 TION SERVICES.—Each eligible child shall  
 3 receive care coordination services (as de-  
 4 fined in subsection (a)(1)) and hospice  
 5 care (as so defined) through an eligible  
 6 provider participating in a demonstration  
 7 project, regardless of whether such indi-  
 8 vidual has been determined to be termi-  
 9 nally ill (as defined in section 1861(dd)(3)  
 10 of the Social Security Act (42 U.S.C.  
 11 1395x(dd)(3))).

12 (iv) AVAILABILITY OF INFORMATION  
 13 ON PEDIATRIC PALLIATIVE CARE.—Each  
 14 eligible child and the family of such child  
 15 shall receive information and education in  
 16 order to better understand the utility of  
 17 pediatric palliative care.

18 (v) AVAILABILITY OF BEREAVEMENT  
 19 COUNSELING.—Each family of an eligible  
 20 child shall receive bereavement counseling,  
 21 if appropriate.

22 (vi) ADDITIONAL BENEFITS.—Under  
 23 the demonstration projects, the Secretary  
 24 may include any other item or service—

1 (I) for which payment may other-  
 2 wise be made under the medicare pro-  
 3 gram; and

4 (II) that is consistent with the  
 5 recommendations contained in the re-  
 6 port published in 2003 by the Insti-  
 7 tute of Medicine of the National  
 8 Academy of Sciences entitled “When  
 9 Children Die: Improving Palliative  
 10 and End-of-Life Care for Children  
 11 and Their Families”.

12 (C) PAYMENT.—

13 (i) ESTABLISHMENT OF PAYMENT  
 14 METHODOLOGY.—The Secretary shall es-  
 15 tablish a methodology for determining the  
 16 amount of payment for pediatric palliative  
 17 care furnished under the demonstration  
 18 projects that is similar to the methodology  
 19 for determining the amount of payment for  
 20 hospice care (as defined in section  
 21 1861(dd)(1) of the Social Security Act (42  
 22 U.S.C. 1395x(dd)(1))) under section  
 23 1814(i) of such Act (42 U.S.C. 1395f(i)),  
 24 except as provided in the following sub-  
 25 clauses:

1 (I) AMOUNT OF PAYMENT.—Sub-  
2 ject to subclauses (II) and (III), the  
3 amount of payment for pediatric pal-  
4 liative care shall be equal to the  
5 amount that would be paid for hospice  
6 care (as so defined), increased by an  
7 appropriate percentage to account for  
8 the additional costs of providing be-  
9 reavement counseling and care coordi-  
10 nation services (as defined in sub-  
11 section (a)(1)).

12 (II) WAIVER OF HOSPICE CAP.—  
13 The limitation under section  
14 1814(i)(2) of the Social Security Act  
15 (42 U.S.C. 1395f(i)(2)) shall not  
16 apply with respect to pediatric pallia-  
17 tive care and amounts paid for pedi-  
18 atric palliative care under this sub-  
19 paragraph shall not be counted  
20 against the cap amount described in  
21 such section.

22 (III) SEPARATE PAYMENT FOR  
23 COUNSELING SERVICES.—Notwith-  
24 standing section 1814(i)(1)(A) of the  
25 Social Security Act (42 U.S.C.

1                   1395f(i)(1)(A)), the Secretary may  
2                   pay for bereavement counseling as a  
3                   separate service.

4                   (ii) SPECIAL RULES FOR PAYMENT OF  
5                   MEDICARE+CHOICE ORGANIZATIONS.—The  
6                   Secretary shall establish procedures under  
7                   which the Secretary provides for an appro-  
8                   priate adjustment in the monthly payments  
9                   made under section 1853 of the Social Se-  
10                  curity Act (42 U.S.C. 1395w–23) to any  
11                  Medicare+Choice organization that pro-  
12                  vides health care items or services to an el-  
13                  igible child who is participating in a dem-  
14                  onstration project.

15                (3) COVERAGE OF PEDIATRIC PALLIATIVE CARE  
16                CONSULTATION SERVICES.—Under the demonstra-  
17                tion projects, the Secretary shall provide for a one-  
18                time payment on behalf of each eligible child who  
19                has not yet elected to participate in the demonstra-  
20                tion project for services that are furnished by a phy-  
21                sician who is either the medical director or an em-  
22                ployee of an eligible provider participating in such a  
23                project and that consist of—

1 (A) an evaluation of the individual's need  
 2 for pain and symptom management, including  
 3 the need for pediatric palliative care;

4 (B) counseling the individual and the fam-  
 5 ily of such individual with respect to the bene-  
 6 fits of pediatric palliative care and care options;  
 7 and

8 (C) if appropriate, advising the individual  
 9 and the family of such individual regarding ad-  
 10 vanced care planning.

11 (d) CONDUCT OF DEMONSTRATION PROJECTS.—

12 (1) SITES.—The Secretary shall conduct dem-  
 13 onstration projects in at least 4, but not more than  
 14 8, sites.

15 (2) SELECTION OF SITES.—The Secretary shall  
 16 select demonstration sites on the basis of proposals  
 17 submitted under paragraph (3) that are located in  
 18 geographic areas that—

19 (A) include both urban and rural eligible  
 20 providers; and

21 (B) are geographically diverse and readily  
 22 accessible to a significant number of eligible  
 23 children.

24 (3) PROPOSALS.—The Secretary shall accept  
 25 proposals to furnish pediatric palliative care under

1 the demonstration projects from any eligible provider  
 2 at such time, in such manner, and in such form as  
 3 the Secretary may reasonably require.

4 (4) FACILITATION OF EVALUATION.—The Sec-  
 5 retary shall design the demonstration projects to fa-  
 6 cilitate the evaluation conducted under subsection  
 7 (e)(1).

8 (5) DURATION.—The Secretary shall complete  
 9 the demonstration projects within a period of 5  
 10 years that includes a period of 1 year during which  
 11 the Secretary shall complete the evaluation under  
 12 subsection (e)(1).

13 (e) EVALUATION AND REPORTS TO CONGRESS.—

14 (1) EVALUATION.—During the 1-year period  
 15 following the first 4 years of the demonstration  
 16 projects, the Secretary shall complete an evaluation  
 17 of the demonstration projects in order—

18 (A) to determine the short-term and long-  
 19 term costs and benefits of changing—

20 (i) hospice care (as defined in section  
 21 1861(dd)(1) of the Social Security Act (42  
 22 U.S.C. 1395x(dd)(1))) provided under the  
 23 medicare program to children to include  
 24 the pediatric palliative care furnished  
 25 under the demonstration projects; and



1 (ii) the medicare program to permit  
2 eligible children to receive curative and pal-  
3 liative care simultaneously;

4 (B) to review the implementation of the  
5 demonstration projects compared to rec-  
6 ommendations contained in the report published  
7 in 2003 by the Institute of Medicine of the Na-  
8 tional Academy of Sciences entitled “When  
9 Children Die: Improving Palliative and End-of-  
10 Life Care for Children and Their Families”;

11 (C) to determine the quality and duration  
12 of palliative care for individuals who receive  
13 such care under the demonstration projects who  
14 would not be eligible to receive such care under  
15 the medicare program;

16 (D) whether any increase in payments for  
17 pediatric palliative care is offset by savings in  
18 other parts of the medicare program; and

19 (E) the projected cost of implementing the  
20 demonstration projects on a national basis.

21 (2) REPORTS.—

22 (A) INTERIM REPORT.—Not later than the  
23 date that is 2 years after the date on which the  
24 demonstration projects are implemented, the

1 Secretary shall submit an interim report to  
2 Congress on the demonstration projects.

3 (B) FINAL REPORT.—Not later than the  
4 date that is 1 year after the date on which the  
5 demonstration projects end, the Secretary shall  
6 submit a final report to Congress on the dem-  
7 onstration projects that includes the results of  
8 the evaluation conducted under paragraph (1)  
9 together with such recommendations for legisla-  
10 tion or administrative action as the Secretary  
11 determines is appropriate.

12 (f) WAIVER OF MEDICARE REQUIREMENTS.—The  
13 Secretary shall waive compliance with such requirements  
14 of the medicare program to the extent and for the period  
15 the Secretary finds necessary to conduct the demonstra-  
16 tion projects.

17 **SEC. 202. PRIVATE SECTOR PEDIATRIC PALLIATIVE CARE**  
18 **DEMONSTRATION PROJECTS.**

19 (a) DEFINITIONS.—In this section:

20 (1) DEMONSTRATION PROJECT.—The term  
21 “demonstration project” means a demonstration  
22 project established by the Secretary under sub-  
23 section (b)(1).

(2) ELIGIBLE CHILD.—The term “eligible child” means an individual with a life-threatening condition who is—

(A) under 18 years of age;

(B) enrolled for health benefits coverage under an eligible health plan; and

(C) not enrolled under (or entitled to) benefits under a health plan described in paragraph (3)(C).

(3) ELIGIBLE HEALTH PLAN.—

(A) IN GENERAL.—Subject to clauses (ii) and (iii), the term “eligible health plan” means an individual or group plan that provides, or pays the cost of, medical care (as such term is defined in section 2791 of the Public Health Service Act (42 U.S.C. 300gg–91)).

(B) TYPES OF PLANS INCLUDED.—For purposes of subparagraph (A), the term “eligible health plan” includes the following health plans, and any combination thereof:

(i) A group health plan (as defined in section 2791(a) of the Public Health Service Act (42 U.S.C. 300gg–91(a))), but only if the plan—

1 (I) has 50 or more participants  
2 (as defined in section 3(7) of the Em-  
3 ployee Retirement Income Security  
4 Act of 1974 (29 U.S.C. 1002(7))); or

5 (II) is administered by an entity  
6 other than the employer who estab-  
7 lished and maintains the plan.

8 (ii) A health insurance issuer (as de-  
9 fined in section 2791(b) of the Public  
10 Health Service Act (42 U.S.C. 300gg-  
11 91(b))).

12 (iii) A health maintenance organiza-  
13 tion (as defined in section 2791(b) of the  
14 Public Health Service Act (42 U.S.C.  
15 300gg-91(b))).

16 (iv) A long-term care policy, including  
17 a nursing home fixed indemnity policy (un-  
18 less the Secretary determines that such a  
19 policy does not provide sufficiently com-  
20 prehensive coverage of a benefit so that the  
21 policy should be treated as a health plan).

22 (v) An employee welfare benefit plan  
23 or any other arrangement which is estab-  
24 lished or maintained for the purpose of of-

1           fering or providing health benefits to the  
2           employees of 2 or more employers.

3           (vi) Health benefits coverage provided  
4           under a contract under the Federal em-  
5           ployees health benefits program under  
6           chapter 89 of title 5, United States Code.

7           (C) TYPES OF PLANS EXCLUDED.—For  
8           purposes of subparagraph (A), the term “eligi-  
9           ble health plan” does not include any of the fol-  
10          lowing health plans:

11           (i) The medicare program under title  
12           XVIII of the Social Security Act (42  
13           U.S.C. 1395 et seq.).

14           (ii) The medicaid program under title  
15           XIX of the Social Security Act (42 U.S.C.  
16           1396 et seq.).

17           (iii) A medicare supplemental policy  
18           (as defined in section 1882(g)(1) of the  
19           Social Security Act (42 U.S.C. 1395ss et  
20           seq.).

21           (iv) The health care program for ac-  
22           tive military personnel under title 10,  
23           United States Code.

1 (v) The veterans health care program  
 2 under chapter 17 of title 38, United States  
 3 Code.

4 (vi) The Civilian Health and Medical  
 5 Program of the Uniformed Services  
 6 (CHAMPUS), as defined in section  
 7 1072(4) of title 10, United States Code.

8 (vii) The Indian health service pro-  
 9 gram under the Indian Health Care Im-  
 10 provement Act (25 U.S.C. 1601 et seq.).

11 (4) ELIGIBLE ORGANIZATION.—The term “eligi-  
 12 ble organization” means an organization that pro-  
 13 vides health benefits coverage under an eligible  
 14 health plan.

15 (5) LIFE-THREATENING CONDITION.—The term  
 16 “life-threatening condition” has the meaning given  
 17 such term under section 201(a)(4).

18 (6) PEDIATRIC PALLIATIVE CARE.—The term  
 19 “pediatric palliative care” means services of the type  
 20 to be furnished under the demonstration projects  
 21 under section 201, including care coordination serv-  
 22 ices (as defined in subsection (a)(1) of such section).

23 (7) PEDIATRIC PALLIATIVE CARE CONSULTA-  
 24 TION SERVICES.—The term “pediatric palliative care

1       consultation services” means services of the type de-  
2       scribed in section 201(c)(3).

3               (8) SECRETARY.—The term “Secretary” means  
4       the Secretary of Health and Human Services, acting  
5       through the Director of the Agency for Healthcare  
6       Research and Quality.

7       (b) NONMEDICARE PEDIATRIC PALLIATIVE CARE  
8 DEMONSTRATION PROJECTS.—

9               (1) ESTABLISHMENT.—The Secretary shall es-  
10       tablish demonstration projects under this section at  
11       the same time as the Secretary establishes the dem-  
12       onstration projects under section 201 and in accord-  
13       ance with the provisions of this subsection to dem-  
14       onstrate the provision of pediatric palliative care and  
15       pediatric palliative care consultation services to eligi-  
16       ble children who are not entitled to (or enrolled for)  
17       coverage under the health plans described in sub-  
18       section (a)(3)(C).

19              (2) PARTICIPATION.—

20               (A) ELIGIBLE ORGANIZATIONS.—The Sec-  
21       retary shall permit any eligible organization to  
22       participate in a demonstration project on a vol-  
23       untary basis.

24               (B) ELIGIBLE CHILDREN.—Any eligible or-  
25       ganization participating in a demonstration

1 project shall permit any eligible child enrolled in  
2 an eligible health plan offered by the organiza-  
3 tion to participate in such project on a vol-  
4 untary basis.

5 (c) SERVICES UNDER DEMONSTRATION  
6 PROJECTS.—

7 (1) PROVISION OF PEDIATRIC PALLIATIVE CARE  
8 AND CONSULTATION SERVICES.—Under a dem-  
9 onstration project, each eligible organization electing  
10 to participate in the demonstration project shall pro-  
11 vide pediatric palliative care and pediatric palliative  
12 care consultation services to each eligible child who  
13 is enrolled with the organization and who elects to  
14 participate in the demonstration project.

15 (2) AVAILABILITY OF ADMINISTRATIVE  
16 GRANTS.—

17 (A) IN GENERAL.—Subject to subpara-  
18 graph (B), the Secretary shall award grants to  
19 eligible organizations electing to participate in a  
20 demonstration project for the administrative  
21 costs incurred by the eligible organization in  
22 participating in the demonstration project, in-  
23 cluding the costs of collecting and submitting  
24 the data required to be submitted under sub-  
25 section (d)(4)(B).



1 (B) NO PAYMENT FOR SERVICES.—The  
2 Secretary may not pay eligible organizations for  
3 pediatric palliative care or pediatric palliative  
4 care consultation services furnished under the  
5 demonstration projects.

6 (d) CONDUCT OF DEMONSTRATION PROJECTS.—

7 (1) SITES.—The Secretary shall conduct dem-  
8 onstration projects in at least 4, but not more than  
9 8, sites.

10 (2) SELECTION OF SITES.—The Secretary shall  
11 select demonstration sites on the basis of proposals  
12 submitted under paragraph (3) that are located in  
13 geographic areas that—

14 (A) include both urban and rural eligible  
15 organizations; and

16 (B) are geographically diverse and readily  
17 accessible to a significant number of eligible  
18 children.

19 (3) PROPOSALS.—

20 (A) IN GENERAL.—The Secretary shall ac-  
21 cept proposals to furnish pediatric palliative  
22 care and pediatric palliative care consultation  
23 services under the demonstration projects from  
24 any eligible organization at such time, in such

1 manner, and in such form as the Secretary may  
2 require.

3 (B) APPLICATION FOR ADMINISTRATIVE  
4 GRANTS.—If the eligible organization desires to  
5 receive an administrative grant under sub-  
6 section (c)(2), the proposal submitted under  
7 subparagraph (A) shall include a request for  
8 the grant, specify the amount requested, and  
9 identify the purposes for which the organization  
10 will use any funds made available under the  
11 grant.

12 (4) COLLECTION AND SUBMISSION OF DATA.—

13 (A) COLLECTION.—Each eligible organiza-  
14 tion participating in a demonstration project  
15 shall collect such data as the Secretary may re-  
16 quire to facilitate the evaluation to be com-  
17 pleted under subsection (e)(1).

18 (B) SUBMISSION.—Each eligible organiza-  
19 tion shall submit the data collected under sub-  
20 paragraph (A) to the Secretary at such time, in  
21 such manner, and in such form as the Secretary  
22 may require.

23 (5) DURATION.—The Secretary shall complete  
24 the demonstration projects within a period of 5  
25 years that includes a period of 1 year during which

1 the Secretary shall complete the evaluation under  
2 subsection (e)(1).

3 (e) EVALUATION AND REPORTS TO CONGRESS AND  
4 ELIGIBLE ORGANIZATIONS.—

5 (1) EVALUATION.—During the 1-year period  
6 following the first 4 years of the demonstration  
7 projects, the Secretary shall complete an evaluation  
8 of the demonstration projects.

9 (2) REPORTS.—

10 (A) INTERIM REPORT.—Not later than the  
11 date that is 2 years after the date on which the  
12 demonstration projects are implemented, the  
13 Secretary shall submit an interim report to  
14 Congress and each eligible organization partici-  
15 pating in a demonstration project on the dem-  
16 onstration projects.

17 (B) FINAL REPORT.—Not later than the  
18 date that is 1 year after the date on which the  
19 demonstration projects end, the Secretary shall  
20 submit a final report to Congress and each eli-  
21 gible organization participating in a demonstra-  
22 tion project on the demonstration projects that  
23 includes the results of the evaluation conducted  
24 under paragraph (1) together with such rec-  
25 ommendations for legislation or administrative

1           action as the Secretary determines is appro-  
2           priate.

3 **SEC. 203. AUTHORIZATION OF APPROPRIATIONS.**

4       (a) IN GENERAL.—There are authorized to be appro-  
5       priated—

6           (1) \$2,500,000, to carry out the demonstration  
7       projects under section 201; and

8           (2) \$2,500,000, to carry out the demonstration  
9       projects under section 202, including for awarding  
10      grants under subsection (c)(2) of such section.

11      (b) AVAILABILITY.—Sums appropriated under sub-  
12      section (a) shall remain available, without fiscal year limi-  
13      tation, until expended.

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